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ABSTRACT

This report is designed to assist state officials in identifying appropriate approaches and resources for meeting the legal requirements for child find and public awareness procedures for identifying children with disabilities. The reauthorized Individuals with Disabilities Education Act requires that the lead agency for Part H in each state disseminate to primary referral sources (particularly hospitals and physicians but also day care programs, social service agencies, and others) information about Part H, the benefits of early intervention, and the availability of early intervention services. The lead agency is also required to determine the extent to which information is made available to parents by primary referral sources. This report's approaches are based on a survey of over 30 Part H state lead agencies and Early Education Program for Children with Disabilities projects. Responses to the survey were consolidated into five functional headings: (1) communication from early intervention programs to medical personnel and health facilities for child find and public awareness purposes; (2) communication to other primary referral sources, specifically nonmedical personnel and facilities, for child find and public awareness purposes; (3) practices found ineffective in communicating with primary referral sources for child find and public awareness purposes; (4) communication from agencies and primary referral sources to families; and (5) gaining feedback about communication with primary rererral sources and evaluating outcomes. Attachments include the survey questions, a list of respondents and reviewers, a list of 11 selected publications and materials, and a reprint of a list of over 65 "Selected References" from "Promoting Health through Part H." (JDD)

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Communicating with Primary Referral Sources: A Synthesis Report

by

Carol Berman and Joan Melner

NEC•TAS

EC 301500

National Early Childhood Technical Assistance System

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The National Early Childhood Technical Assistance System (NEC*TAS)
is a collaborative system, coordinated by

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Purpose and Organization of Report

The purpose of this report is to assist Part H state officials in identifying appropriate approaches and resources as procedures are developed to meet the requirements in the Individuals with Disabilities Education Act and its amendments relating to child find and public awareness procedures.

We sought to uncover practical information about current practices in communicating with primary referral sources, using a simple survey of individuals and organizations that are engaged in statewide Part H planning, or that are conducting projects which enhance early intervention services.

This report is not intended to be a comprehensive state-of-the-art summary. Rather, it consolidates information and ideas about communication with primary referral sources that may serve to inform state planning.

In addition to the statement of purpose and organization, the report consists of four sections: Background, Methodology, Results, and Conclusions (which includes questions for future discussion). Also included are four attachments: A is a list of the questions included in the request for resources survey; B is an annotated list of respondents; C is a list of selected additional resources; and D is a bibliography reprinted from the NEC*TAS/NCCIP publication, *Promoting Health Through Part H*.

Background

Medical personnel (such as obstetricians, nurses, and pediatricians), and nonmedical personnel (such as child care providers, social workers, and community advocates) may be the first people outside of the child's family to suspect or identify that a child has a developmental delay or is at risk for such a delay. Often these personnel are not aware of the range of available early intervention services in the community and state. Sometimes such personnel may be unaware of the Part H program, or of the benefits of early intervention services.

In the 1990 reauthorization of the IDEA, the Congress added statutory language concerning primary referral resources to three of the 14 components required in the Infants and Toddlers with Disabilities Program (Part H). The three components affected are public awareness, child find, and a comprehensive system of personnel development.

The *child find* and *public awareness* components of the Act [Section 676 (b)(5) and (6)] now include a requirement that the lead agency for Part H in each state disseminate to primary referral sources, particularly hospitals and physicians, information on the availability of early intervention services. (Regulations concerning child find define primary referral sources also to include parents, day care programs, local education agencies, public health facilities, other social service agencies, and other health care providers. [See 34 CFR 303.321 (d)(3)]) The lead agency for Part H is expected to be an active communicator; in addition to disseminating information (about Part H, the benefits of early intervention, and the availability of services) *to* primary referral sources, the agency is to determine the extent to which information is made available to parents *by* primary referral sources.

The third new requirement pertaining to primary referral sources applies to the *comprehensive system of personnel development* (CSPD) component [Section 676 (b)(8)]. Specifically, the CSPD developed by the lead agency must include information about the training of primary referral sources in the basic components of early intervention services.

Methodology

This report represents an effort to bring together the knowledge base from Part H state lead agencies and EEPCD (Early Education Program for Children with Disabilities) projects which are working principally at the local level. To tap this resource, an eleven-question "request for resources" announcement was developed by the authors, in consultation with Peggy Cvach, project officer in the Early Childhood Branch, Office of Special Education Programs (OSEP); Pascal Trohanis, Principal Investigator of the National Early Childhood Technical Assistance System (NEC*TAS); and NEC*TAS staff who commonly respond to inquiries relating to child identification. The instrument was designed to elicit information about existing procedures which have helped to make primary referral sources more aware of early intervention services, Part H, and the benefits of early intervention.

The survey included seven questions asking for descriptions of practices, three questions relating to evaluation and outcome data, and one question about products. As suggested by the title of the announcement and this report, the focus of the questions was mainly on "communication" with primary referral sources. Hence, although the requirement in the CSPD component was of interest, the "request for resources" questions mainly emphasized the public awareness and child find components. A list of the questions can be found in Attachment A.

The announcement and survey were distributed in November, 1991, to EEPCD projects and institutes and to state Part H lead agencies. The announcement promised a report, to be distributed to Part H officials in 1992. Two national Maternal and Child Health (MCH) resource centers also were sent a copy of the survey and were asked to identify special projects of regional and national significance (SPRANS) which were especially germane. On January 15, 1992, at the OSEP-NEC*TAS combined meeting of personnel in EEPCD projects and Part H and Part B (Section 619) programs in Baltimore, a 90-minute workshop on public awareness and the use of primary referral sources provided an opportunity for open discussion on this subject and helped refine and shape further inquiry.

NEC*TAS subsequently conducted several interviews to glean information about work in progress. One was with Patricia Fullagar, who, as part of the Carolina Policy Studies Program located in Chapel Hill, NC, has been studying the relationship between Part H and health care system providers. Another was Haidee Bernstein, who is conducting a case study of Part H public awareness initiatives in six states for her doctoral dissertation at the University of Maryland. A third interview was conducted with Margaret Summerfelt of the National Easter Seal Society in Illinois, whose "Watch Me Grow" SPRANS grant was identified by both national MCH resource centers. Finally, an interview also was conducted with Renee Wachtel of the University of Maryland Department of Pediatrics, where pediatric residents receive training that addresses early intervention issues.

Results of over 30 written responses and interviews were synthesized and reframed into a brief narrative that generally followed the outline of the survey questions. Additional facts known to the NEC*TAS topic team on child identification were added once the preliminary narrative was formulated. At this point, the draft was subjected to review by individuals and organizations. (A list of respondents, interviewees, and reviewers is provided in Attachment B. These include 15 state agencies, 16 EEPCD and SPRANS projects, and 8 other individuals and organizations.)

Results

Results of the survey, interviews, and reviewers' comments are not reported along each of the eleven questions asked in the survey. Rather, five functional headings, which consolidate responses to questions, have been used. These include (1) communication from early intervention programs or projects to medical personnel and health facilities for child find and public awareness purposes; (2) communication to other primary referral sources, specifically nonmedical personnel and facilities (e.g., child care workers, social service professionals, local education agencies, family support programs and families) for child find and public awareness purposes; (3) what doesn't work in communicating with primary referral sources for child find and public awareness purposes; (4) communication from agencies and primary referral sources to families; and (5) gaining feedback about communication with primary referral sources and evaluating outcomes.

As might be expected, responses from EEPCD projects related to ways that locally based programs connect with primary service providers, training of providers in specific service locations (such as a Neonatal Intensive Care Unit), or other local applications. In contrast, responses from Part H program staff tended to describe statewide systems. This report uses examples offered by Part H and project respondents, as well as interviewees, and is punctuated with illustrations and suggestions made by reviewers with diverse areas of expertise. Examples and ideas are attributed to states, projects, or individuals as seems appropriate or helpful.

Communication from Early Intervention Programs or Projects to Medical Personnel and Health Facilities for Child Find and Public Awareness Purposes

We were interested in ways in which projects, models, or agencies disseminated to medical personnel/health facilities information regarding early intervention services/resources, and educated them on the benefits of collaboration between early intervention programs and primary referral sources. While our questions did not ask for responses that were specific to the public and private sectors of the health care system, we were aware that both sectors are central in many states to child identification and referral for early intervention.

Based on our review and analysis of responses, we determined that a basic and important consideration about communication from early intervention programs to physicians and other health care providers is the recognition that the health care "system" was here before Part H, and that it is large and may be structured differently. Expecting primary referral sources to "fit into" the Part H service delivery system may be like trying to put a jacket on a foot. It is not a natural match. Part H programs need to accommodate the health care system and seek to work cooperatively.

Within this context, some accommodations made by early intervention programs to health care providers included the following:

Respect for time. One project director commented that until salaries of early intervention personnel exceed those of the physicians in the health care system, she views the per hour cost of physician's time as greater. Moreover, physicians' schedules tend to be extremely full. These factors suggest the wisdom of keeping reports succinct, and offering to hold IFSP meetings in medical offices, so that physicians may attend.

Understanding the culture of the health care system. One project suggested that the term "referral" for health care providers may mean the child is sent elsewhere for a second opinion or other services. Within the health care system, that referral may be construed as an implied loss, and perhaps even liability. Instead, physicians and nurses might be "asked for help sharing information with families" about early intervention services. If a physician is concerned with loss of his or her role as the child's primary health care provider, it will be important to make assurances that this will not occur--that there is a connection back to the health care provider.

At Child Development Resources (CDR) in Virginia, each physician is routinely thanked for allowing the early intervention program to see his or her patient, as a way of acknowledging the physician's primary medical case management/service coordination role. Succinct evaluation and progress reports are the norm in the medical community. Each time a child is assessed and a new IFSP is written, parents are encouraged by CDR to take a copy to the physician or sign a release so that the program can send a copy. The cover letter invites the physician's participation in a variety of ways, as time permits: attend the conference, review the IFSP, and comment.

The Part H program in Maine suggested having a tear-off at the back of the IFSP, as a convenient way to return a summary to the primary referral source, eliciting a sign-off as a notice of the physician's review and service authorization. In the experience of another Part H program, an early intervention program located in a school district may be less accustomed to providing physicians with regular progress reports, may not be as aware of these expectations, and may have less regard for the role of the health care provider on the team.

Playing a pivotal role in the referral process are public health nurses, who possess a combination of expertise in patient care and familiarity with community resources. Many respondents pointed out that public health nurses and other maternal and child health agency staff serve as a natural link between the medical profession and early intervention programs because they traditionally have interacted with both. Moreover, since most counties have public health nurses, this is potentially a consistent child find vehicle within and across states.

Ongoing communication. The need for ongoing communication is underscored by the fragile financial status of some early intervention programs, high rate of staff turnover, and low salaries. Some medical/health primary referral sources may not be certain that a local program will be there when a referral is made. Regular communication from early intervention programs may serve to convince primary referral sources of the value and enduring nature of early intervention services. For example, in North Carolina, the central directory of resources for Part H is operated by the Family Support Network of the University of North Carolina Medical School's Pediatrics Department, thus providing a means for keeping the Department connected and up-to-date on early intervention services.

A wealth of ideas for communicating with primary referral sources were suggested. We have included some of them below.

- General information/mailings. Disseminating literature about Part H and early intervention services is a requirement of the public awareness provision of IDEA. Typically, information about IDEA and the state Part H program is conveyed through directories of resources, brochures containing a toll-free number and information about the directory, or some combination of these materials. Kansas' Part H program sends packages of brochures to pediatricians, family practitioners, local health departments, education and social service agencies, and family support programs. New York State plans to include information on referral procedures in its mailing to physicians. The North Dakota Early Childhood Tracking System (NDECTS) believes that brochures are viewed by medical personnel as helpful in their contacts with parents. Maine's brochures are placed in health care facilities, and include information about the "child development system" (Part H & Section 619 of Part B), location of services, and the role of health professionals.

- Newsletters. Sending a newsletter to medical/health personnel on a regular basis offers one means of ongoing communication. The Kansas Part H program distributes statewide a monthly newsletter, "It's News," which contains information about procedures, policy, materials, and innovative strategies. An outreach project in Tennessee sends a newsletter about

early intervention and other programs to maternal and infant programs in six states. North Carolina's Part H program strives to get information about Part H and available services included in newsletters published by the various professional groups representing primary referral sources. Minnesota's Part H program just started to send a quarterly newsletter to family practice physicians in December 1991. In Colorado, the state chapter of the American Academy of Pediatrics (AAP) joined with the Department of Education, which is the Part H lead agency, in publishing "Physicians, Kids and 99-457," a newsletter that communicates about early intervention and Part H.

The newsletter distributed in Illinois, called "Early Intervention: Quarterly Newsletter of the Illinois Early Childhood Intervention Clearinghouse," is a project of the Illinois Public Health Association. Content of a sample issue includes a legislative update on the Early Intervention Systems Act (state legislation), a report on "Family Day," a rally for supporters of the new state law, updates and call for comments on the preschool state plan, a report on the state ICC meeting, book and videotape reviews (three of four had physician editors or authors), a call for the inclusion of speakers and trainers in a statewide central resource directory, a calendar of conferences, workshops, council meetings and other events, and a list of materials found in the Clearinghouse (jointly funded by the Illinois State Board of Education and the Illinois Planning Council on Developmental Disabilities).

- Peer networks. Involving members of the health community in the development and dissemination of materials can be valuable. Some participants in the Carolina Policy Studies Program's focus group of health providers, facilitated by Patricia Fullagar, spoke of "detailing" physicians who are knowledgeable about early intervention, and charging them to encourage colleagues to become more interested and involved in Part H. In North Carolina, a corporate grant funded a pediatrician on the ICC to develop child find/public awareness materials aimed at a broad audience including the medical community. Similarly, a physician on the advisory board of an outreach project in North Carolina helped with a mailing to physicians in the community.

In Maine, a flow chart of the service process, from child identification through service provision, was developed. An advisory group of physicians used this chart to recommend at which points physicians should be informed about their patients or be active participants in the process. The advisors have taken responsibility for working with their peers.

In Ohio, one of several states in which the lead agency for Part H is housed in the Health Department, a program advisory committee to the Title V Children with Special Health Care Needs (CSHCN) program has focused on recruiting local medical providers to work with the Title V program, which works closely with Part H. The committee is comprised mainly of pediatricians, and includes other medical specialties, advocates, other agency representatives, and parents.

An EEPCD project with referrals largely from hospitals reminded us not to overlook building relationships with individuals who are not at the top of the hospital or clinic hierarchy but who have very regular contact with families, such as discharge planners, child life specialists, occupational therapists, physical therapists, nurses and nursing aides.

- Annual awareness campaigns. Whether the strategy is use of printed materials, site visits, training, or planning groups, the timetable for communication needs to be given consideration. A project in Ohio cited an annual awareness campaign in which brochures are disseminated. The CESA Project in Portage, Wisconsin provides information and screening at joint functions, such as a "county health day." Wyoming mentioned an annual infant conference, in which health care professionals are included to the extent possible. Such events can make an expanded group of referral sources more aware of early intervention services.

- Personal contact with primary referral sources. At least one project pointed out that just handing out written materials is not enough. Systematic follow-up is needed. Moreover, planning a system of exchange of information, implementation of this system and ensuring its success took a good deal of information sharing and trust building with all involved personnel. Consistent, regular exchanges of information can be particularly important in planning and implementing local or regional programs. In Maine, a health advisory group was formed two years ago to examine how physicians and other health care professionals could plan for a stronger role in the field of early intervention and establish procedures for ongoing communication among the participating agencies.

- Training. Some of the projects that responded to the survey were specifically funded to train personnel who are primary referral sources. A state health department-funded project in Arizona has developed a module which was presented to 650 physicians and other health personnel in 27 sites. Currently, this project is developing a protocol for use by primary care physicians in screening behavioral problems. A project in New Mexico is developing a training module that targets primary care providers in teaching "early sorting and referral and resource awareness." The Kansas BEST project provides training for local interagency planning in which personal contact is established between early intervention professionals and their counterparts in medical facilities. CDR in Virginia recently received EEPCD funding to provide inservice training to physicians in coordination with the state chapters of the Academy of Family Physicians and the Academy of Pediatrics.

The Wyoming Health Department recently received a three-year grant to educate health care providers regarding early intervention and available services. The training will be multidisciplinary and community based.

The Illinois Part H program supports a technical assistance project (ITAP) in which medical/health issues are taught by a physician, which in their view will make attendance by medical personnel more likely. New York State Part H also has funded a technical assistance project to conduct workshops. Kansas Part H contracted with the medical school to facilitate preservice and inservice training for physicians and developed a procedural manual that was distributed to many primary referral sources statewide. In Maryland, the Part H program has initiated a series of technical assistance conferences and on-site poster sessions to facilitate the referral process from neonatal intensive care units (NICUs) and Pediatric Intensive Care Programs (PICUs). These are scheduled to accommodate all work shifts.

T. Berry Brazelton, a reviewer of this synthesis report, mentioned two approaches that have particular merit. One is a "road show" in which he gives a talk to some 1500 parents and then is joined by three colleagues to talk with 300-400 professionals, typically about the value

of early referrals. He reaches large audiences this way and has found that these parents will self-refer. While not every pediatrician attracts these numbers, the concept of combining parent education and professional meetings may be a useful and overlooked strategy for outreach to grassroots audiences. Brazelton's second observation was that training of head nurses in the use of his Neonatal Behavior Assessment Scale was productive in generating direct referrals of high-risk infants to early intervention services. The head nurses trained nursery nurses from surrounding hospitals, who then made referrals of families for early intervention. Brazelton noted, "NICU nurses are the key to these early referrals."

Physicians in teaching hospitals often are trained through observation of personnel in clinics or attendance at grand rounds. Some child find practitioners have been able to develop mutual trust and respect with physicians, resulting in increased referrals, rapport, and utilization of early intervention services. They have earned standing orders from physicians for evaluations and garnered invitations to present at grand rounds. Some have indicated that this acceptance has tended to be greater in rural facilities; sometimes it is gained through intermediaries, such as nurse practitioners.

The importance of ongoing training in early intervention for medical personnel is acknowledged readily by these personnel themselves. In a study conducted by the Carolina Policy Studies Program, Patricia Fullagar found physicians and nurses to be critical of their own backgrounds and training. A modal response of physicians was, "Whatever I know about early intervention has been gained since my residency."

We did not attempt to catalog or evaluate the numerous training programs for physicians, but it seems valuable to mention three programs that were cited as examples of training approaches that are contributing to greater understanding of early childhood disabilities and intervention programs. The Medical Home Project of the Hawaii Medical Association illustrates a community-based, continuing education approach. These seminars address the major components of referral: early identification, how to refer, and how to work as a team with local programs. Training programs developed at the University of Maryland Department of Pediatrics and the medical school curriculum at University of North Carolina at Chapel Hill which provide preservice training to medical students and residents. The University of Maryland curriculum, which includes preservice and inservice training, exposes all medical students to content on developmental disabilities, early detection and early intervention. The pediatric residency program emphasizes normative development in the first year, trains residents to distinguish among disabilities and visit several sites in the second year, and strongly features the pediatrician as part of the team in the third year. The UNC-CH program, which has been in existence for several years, requires medical students to spend time in early intervention programs and provide respite to parents of children with severe physical or mental disability.

The growth in training programs spans the health professions. Physicians have responded to the need quickly, and pediatricians seem to have taken a lead among the medical community concerned with infants and toddlers in showing interest in Part H. Among federal initiatives, the U.S. Department of Health and Human Services supports University Affiliated Programs (UAPs), which are mandated to provide training for all pediatric residents and medical students with emphases in developmental issues relating to special health care needs, including developmental disabilities and major disabling conditions.

A number of professional organizations also emphasize training. The American Academy of Pediatrics (AAP) and the Maternal and Child Health Bureau (MCHB) have co-sponsored national meetings on the role of physicians (see Attachment C, Selected Additional Resources). AAP also has developed and distributed notebooks and other materials to its state chapters to train physicians about early intervention and early identification. The journal, *Pediatrics*, lists fellowship training programs in developmental pediatrics, behavioral pediatrics and child development.

Similar efforts have been made by the American Nurses Association, which has developed a standards document on nurses' roles in early intervention, and by associations representing allied health disciplines. The National Association of Pediatric Nurse Associates and Practitioners (NAPNAP) was identified by reviewers as a key resource in this regard.

Among multidisciplinary professionals, two organizations were noted. The American Association of University Affiliated Programs (AAUAP) is a network of multidisciplinary professionals committed to fostering training and communication. The Association of Maternal and Child Health Programs (AMCHP) assists with documenting and assessing the impact of Title V (of the Social Security Act) programs, and plays a key role in keeping participating Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHN) programs informed.

Communication to Other Primary Referral Sources, Specifically Nonmedical Personnel and Facilities for Child Find and Public Awareness Purposes

We asked respondents to describe how they communicate with nonmedical communities programs and community services agencies, families), if the method differs from the way in which they communicate with the medical and health communities. We wondered whether the medical/health community presented a discrete set of issues. We found that the principles were largely the same in relating to all primary referral sources. Features that may be unique to the health care system, such as medical school training programs, have parallels in other service systems.

Who are the "nonmedical" primary referral sources?

For the purpose of this paper, "nonmedical" primary referral sources were defined as child care providers, social workers, community advocates, and others who come in contact with the community and children on a regular basis. It is useful to consider the wide range of primary referral sources mentioned. Some respondents identified specific community resources that are a target for referral to early intervention. In addition to medical/health professionals and parents, most commonly mentioned were child care providers.

Referral source prospects in child find and public awareness initiatives can be diverse. Although police are not usually considered primary referral sources, in one community with a creative child find program, they are. Child find staff learned that the police carried little books with resource information to use when they encountered families with problems for which they

with resource information to use when they encountered families with problems for which they can suggest help. They got permission to include an inexpensive insert with the child find information and phone number, in the size and style of the book, in case the police encountered children in obvious need of early intervention or special education. The availability of such information resulted in an increase in referrals from that community.

Social service agencies (particularly those administering Medicaid) are a fairly common referral source. One respondent speculated that this may be more likely because of awareness gained through interagency collaborative work than deliberate child find/public awareness campaign strategies. Social service agencies and organizations may include state and local offices administering entitlements (e.g., Aid to Families with Dependent Children (AFDC), the Job Training Partnership Act (JTPA), and Medicaid), offices of minority organizations (e.g., the National Council of La Raza and the National Puerto Rican Coalition), churches and religious organizations (e.g., Catholic Charities, Jewish Child and Family Services), charitable coalitions (e.g., relief for homeless families) and others. All can be primary referral sources, and can be particularly helpful in identifying eligible children from traditionally underserved families.

Family "drop-in" or resource centers--sometimes based in schools, churches, and neighborhood community centers, where families congregate regularly--are important public awareness and child find resources. Family facilitators (parent-to-parent programs) also are seen as an important source of referrals.

How are diverse referrals obtained and handled?

In the workshop on primary referral sources in Baltimore, one participant noted, "Anyone in the community can be a primary referral source." Indeed, community-wide prevention programs in which screening "events" are held to attract all children, age birth to 5 years, without respect to income and other limitations are examples of activities that are consistent with this view of child find. We heard of enterprising events involving merchants, schools, churches, landlords, foundations, and others. In one community, all children are eligible to be screened, but recognizing that some neighborhoods with high risk populations would have more difficulty getting to the screening, the school system provided transportation to selected areas. One project mentioned the need to understand a community's culture and to use all possible resources. McDonalds, Burger King, K Mart, and laundromats have been used for first-level screenings by volunteers. An advocate for this approach commented, "If 200 children are screened, and one child needs early intervention services, then there are still 199 people who learned about early intervention and don't mind paying taxes to support it."

In Washington State, a transmittal letter describing the availability of Interim Family Resources Coordinators (IFRCs) was distributed to personnel in the various agencies, including the Medical Assistance Administration. IFRCs assist families in accessing child find, evaluation and assessment, and development of the IFSP if the child is found to be eligible.

Project Coach in Mississippi, which specializes in work with the child care community, conducts a survey to determine child care centers' needs, and also presents an awareness program at each interested center. They have found that an in-person approach has been more

effective than written materials alone.

The North Carolina Part H program's approaches to child care providers have included: a) presentations about the Part H program and Americans with Disabilities Act (ADA) at state day care related professional organizations such as North Carolina's day care association, the North Carolina Chapter of the Association for the Education of Young Children, and the Child Care Resource and Referral Network; b) development of written information related to P.L. 99-457 for inclusion in written communications such as the newsletter disseminated by the state day care agency to all licensed day care centers and family day care homes; and c) modification of state day care policies to encourage day care providers to identify and serve special needs children. Examples of such policies proposed or approved include 1) establishing a 4.5% "set-aside" of the new Federal day care funds for special needs children; 2) having the state day care agency use the same special needs definition as the Part H lead agency; and 3) establishing a higher (75% increase) purchase-of-care rate for special needs children. North Carolina's Part H lead agency also has an interagency agreement which stipulates that the state and local levels of all signatory agencies have responsibility for training their primary referral sources. Further, the lead agency sets aside staff development funds for training of day care providers through regional workshops, on-site technical assistance, and development of community college curricula.

In Maryland, the Part H program has a single point of entry into early intervention for each county. Information about early intervention and about child development in general is distributed broadly (to families, to prospective primary referral sources at fairs, through public service announcements, newsletters, and other informal mechanisms). Various brochures identify each county's contact person, as the single point of entry into early intervention. This approach for structuring referrals suggests that anyone can recommend that the Part H program see the infant and toddler, but a referral is not formally made until it goes through the single point of entry.

We did not ask a specific question about guidelines for referrals, but did become aware, as we reviewed responses, that there seems to be room for interpretation as to what constitutes a referral. In a view of public awareness and child find that regards <u>everyone</u> in the community as a potential primary referral source for early intervention, the statewide system needs to plan how it will be responsive and what will be the requirements with respect to parent consent and participation.

In Maryland, guidelines for use by NICUs, PICUs, and early intervention systems in referral and discharge planning are being finalized by a workgroup comprised of NICU staff and appropriate state agency staff from the Maryland Infant and Toddler Program (Part H) and the Department of Health and Mental Hygiene.

What Doesn't Work in Communicating with Primary Referral Sources for Child Find and Public Awareness Purposes

We asked respondents to express their judgment about what does not work, based on their experiences. While many respondents left the answer blank, we did receive some useful insights from respondents and reviewers. These can be described as five "losing" approaches to "winning over" primary referral sources:

- Singular approaches are less likely to be effective. One EEPCD training project suggested using a combination of presentations at conferences, newsletters, or during participation in grand rounds, rather than implementing any one of these approaches alone. An interagency coordination project indicated that "one-shot" meetings to talk about early intervention programs are unlikely to result in consistent referrals.

- Insensitivity to time constraints and the culture of the system invites resistance. One project warned against expecting physicians in private practice to attend multidisciplinary workshops or planning council meetings. In this regard, a statewide Part H program admitted that reliance on "too busy" people was a shortcoming. A project suggested that ancillary health care personnel who work closely with physicians and nurses, including therapists and support personnel, may be reliable planners and referral sources; the problem is that they are too often overlooked. A project working with child care providers suggests nap time as the best time to talk with the busy child care staff, when staff can more easily focus their attention on the topic of early childhood.

- Considering any of the suggested approaches as universally applicable courts failure. Mailings without follow-up are seen as having mixed success by some. While office visits and invitations to participate in IFSP meetings and consultations are a logical form of follow-up, some projects warn that these also bring mixed reactions. While some physicians may view these strategies as intrusive, others expect to be included.

- Overlooking the cultural diversity and range of organizations in a community results in a lost opportunity. While an array of strategies for reaching the mainstream culture may be in place, failure to include community leaders, clergy, child advocates, and parent-to-parent support from diverse cultures may result in missed opportunities to inform traditionally underserved populations about Part H, and to obtain referrals for early intervention for young children with great need who might otherwise be overlooked.

- Not taking advantage of all potential resources, including those that existed prior to enactment of Part H, is short-sighted. It is possible to disregard years of prior collaboration, coordination and networking when developing new plans. To do so can be disastrous, since program planners thereby lose out on prior experience, miss connections among agencies and providers, and don't find out about previous failures or successes. For example, coordination among networks such as Title V agencies (Maternal and Child Health and Programs for Children with Special Health Care Needs) with WIC, EPSDT and Medicaid has been a longstanding tradition. Public health agencies and personnel interact with a range of health and health-related primary care providers who are key referral sources for Part H.

Communication from Agencies and Primary Referral Sources to Families

While there is no assurance that sending literature to prospective referral sources will have a positive effect, Part H lead agencies are required to have a method to assure that information reaches families. We asked programs how families receive information about early intervention from primary referral sources in the community. Both projects and lead agencies, have taken steps to encourage dissemination to families of the materials they provide to health clinics, child care centers, community-based organizations, and other prospective referral sources.

A common practice of early intervention programs for facilitating communication to families about early intervention is the provision of appealing materials. Colorful and easy to use wheels illustrating developmental milestones have been provided in several states. Pencils, puzzles, and telephone-shaped magnets that include the toll-free number for referral to early intervention are used by "Sooner Start," the Oklahoma Part H program. A few projects indicated that they tried to be sure that each prospective referring agency has brochures and parent guides to pass along to families. One project calls semiannually to see if replenishment is needed. An innovation of the Southeast Kansas Birth to Three Project of the University Affiliated Program at Parsons is color-coded, easily identified referral packets that include brochures, simple-to-complete referrals and release forms. The same logo is placed on telephone index reference cards, which are sent to primary referral sources. "Babykits" are distributed to all families who deliver a baby in the project's region. The kit--a bag with the project's logo on one side and a drawing of a face used for visual stimulation on the reverse side--includes literature, a washable rattle, a magnet, and a card requesting feedback.

A number of states have produced public service announcements (PSAs) for radio and television in an attempt to reach the mass media market. These have had mixed results, particularly when spots were aired at times other than primetime. While some states have received primetime airings, one respondent lamented that cost-free PSAs have tended to be shown between the hours of 2 and 5 in the morning.

Some states have posted messages about early intervention on buses. Several states have produced wall calendars which outline developmental milestones and suggest developmentally appropriate play activities by age group. A common custom is the inclusion of a statewide telephone number on materials. Another practice of note is translating materials into languages that reflect the cultural diversity of the community or state. Colorado's First Lady sends a congratulatory card as part of its "First Impressions" campaign, welcoming new parents and including brochures on child development and immunization.

Projects are creative in presenting information of value to families. For instance, a UAP project in Hattiesburg, MS, supplies cards for health care staff to give to families. The cards contain information about a free community screening clinic and professional support for child care placements. Agencies are encouraged to keep materials in their waiting rooms. If the professional in the referring agency wishes, the project is willing to send a staff member on a joint visit to the family to discuss services. In the absence of a telephone, the project fosters communication by seeing that messages are carried from one agency to the next.

The Omnibus Budget and Reconciliation Act of 1989 (OBRA '89), which amended Title V of the Social Security Act, has required the use of toll-free hotlines by state public health agencies. The Association of Maternal and Child Health Programs (AMCH) reports that a number of states are using these lines to make referrals to early intervention services. It has been suggested that states may use this same toll-free number to meet the requirements of Part H and OBRA '89.

Gaining Feedback about Communication with Primary Referral Sources and Evaluating Outcomes

The Part H lead agency is expected to determine the extent to which information about early intervention services is made available to parents by primary referral sources. This is particularly challenging, since Part H does not obligate primary referral sources to collect or provide such data. We asked respondents to describe their evaluation components for assessing communication with primary referral sources. We were interested in learning how agencies or projects determine whether information has reached primary referral sources and whether information has reached families.

Feedback Mechanisms

Perhaps because the requirement is new and challenging, we found that many respondents had relatively little to report in answer to these questions. Projects and state systems are mainly at the planning or data collection stage. Few have outcomes to report, although some reported plans for data collection that may yield rich information in the future. For example, North Dakota's Early Childhood Tracking System (NDECTS) hopes to have demographic data on the entire referral process for 5000 children when the system is fully implemented. The BEST project in McPherson, KS, has conducted a statewide study of NICU referrals, and data are currently being analyzed. Some projects and state Part H agencies rely principally on networking and informal mechanisms for evaluating communication with primary referral sources.

Our question was sufficiently general so as to produce responses relating to many different aspects of communication with primary referral sources.

Determining how families learned about early intervention. Most commonly, we found a determination of how families learned about their early intervention services was made by noting the referral sources.

In Colorado, a state-level tracking project has coded referral sources, so that community early intervention programs can readily enter a referral source from the narrative report. For example, a report which states "Henry Jones of Foster Community Hospital referred this three-year-old child...." would be coded for entry as to the referral source from among the following choices: education, public health, social services, hospital, birth defects registry, community center board, family/parents, physician, other health care provider, other community agency, community clinic, and other. Obviously, it is possible that more than one choice could be coded. The system is designed to permit communities to decide what is most helpful to them. In the

absence of funding for participation, agencies must want and need to use the system. Agencies can add modules, so that the tracking system is adaptable to program and community idiosyncracies. The project director points out that it would not serve the state well to dictate how local programs comply.

Computerized information systems designed for identification and tracking of infants at risk for or with disabilities and for ongoing intervention can include data about referral sources. For example, North Carolina's lead agency client information system includes data on referral source. The statistics that were gleaned from their study of principal referral sources are included in the next section (see Evaluation Outcome Results Reported). The "Watch Me Grow" project of the National Easter Seal Society has pilot tested an approach to identifying and tracking at-risk infants. The pilot, which estimated that tracking could be accomplished at a cost of $70 per child, is now being demonstrated in eight sites in Ohio. A program evaluation system is being developed, and a computer database will be used to administer the program and collect longitudinal data. The project asks referral sources such as NICUs to obtain parental consent to share information. The Infant Monitoring Questionnaire (IMQ, Bricker) is sent to parents at four-month intervals; infants needing further evaluation are assessed with the Mullen Scales. Communication is maintained with the primary care physician. There is the potential to use the computer to aid in sending letters and questionnaires, obtaining questionnaire scores, notifying physicians, identifying referral sources, and indicating whether or not parents responded.

Monitoring whether child find and public awareness materials have been used. Processes for noting whether public awareness and child find materials have been used include keeping track of whether programs request additional materials, and monitoring increases in referral rates. Wisconsin's CESA project collects information on brochures delivered and referrals received. The Maryland Infants and Toddlers Program (Part H) maintains records at the state and local level on quantity of public awareness materials distributed to specific primary referral sources, and makes quarterly contact to monitor quantities distributed. During the initial contact with the referred child's family, it is the responsibility of the interim case manager to ask how the family was informed about the availability of early intervention services. The local referral process determines the manner in which the response is recorded.

The Illinois Part H program conducted a study of provider and parent responses to its "Look what I can do" public awareness campaign. Out of 45 surveys sent to providers, there were 24 responses. Out of 40 surveys sent to parents, 8 responses were received. These surveys were essentially requests for feedback on the campaign. Responses from providers indicated that they wanted more advance notice of the public awareness campaign, but praised the briefing book and brochure, and noted that the materials were helpful for planning a local campaign. Parents enthusiastically suggested further activity.

The fourth-year Part H application from Washington State provided interesting results of a study of various approaches to public awareness, in which ratings as to effectiveness and cost were applied. We did not seek to learn how parameters were defined, nor whether various approaches were rated by diverse target audiences, but find the concept of such a list potentially helpful to states for considering and comparing possible approaches. Cost is rated on a scale of $ to $$$, from least to most expensive; effectiveness was rated on a scale of * to ***, from low

to high. The effectiveness ratings, according to the table, are based on private industry standards and the amount of funds available to provide a sustained effort. Examples of approaches rated are shown in the following abbreviated table:

Mechanism	Cost	Effectiveness
1-800 Toll free number	$$$	**
Bags, printed	$	***
Brochure	$	***
Bus Signage	$$	***
Community blue pages	$	***
Community resource fairs	$	**
Community screenings	$$$	**
Direct mail insert	$	*
Flyers in agency lobby	$	***
Flyers in medical office	$	***
Flyers from school	$	***
Flyers in community	$	**
Grassroots lobbying	$	***
Letters to editor	$	***
Mall displays	$$	***

Gathering feedback about the child identification process. The lead agency for Part H in Colorado, the Department of Education, in collaboration with the early childhood interagency task force, including parents, created a self-evaluation tool for their child identification process. This tool contains six "effectiveness indicators" which include interagency collaboration and public awareness, and five "strong values based" components, including a proactive process component and an honor and investment in families component.

CDR in Lightfoot, VA, has conducted formal evaluations, using external consultants. They developed a questionnaire asking parents about communication with primary referral sources, and another about communication with the agencies. They also have conducted a community needs survey. CDR finds its local ICC a useful forum for assessing outcomes and finds that, in teaching hospitals, team reviews of interagency agreements are helpful in this respect. CDR plans to evaluate its training of physicians by asking participating physicians, program coordinators, and parents to complete pre- and post-project questionnaires about physician competencies in the four areas addressed by the training: child find, assessment, IFSP and transition.

In order to gain feedback about how the child identification process is working, it is important to maintain ongoing communication with primary referral sources. One project, at the Kansas UAP, assigns one team member this task. In Tennessee, the Magnolia Circle Outreach project uses feedback from the advisory committee to informally evaluate the project's activities, documents services on a contact sheet with narrative, and uses consumer evaluations of project services.

In Texas, the Part H lead agency (ECI, or the Early Childhood Intervention Council)

reported data on referral sources. Two Texas Regional ECI Consortia conducted surveys of physicians in their geographic areas, and included questions on physician knowledge of the ECI program as well as questions about referral practices. Texas routinely monitors various aspects of its early intervention programs. This monitoring includes calls to referral sources to discuss their relationship with the program and how the referral process is working. Feedback concerning how families are informed may be received during these calls. Anecdotal feedback from ICC committee members has been helpful in answering such questions as well.

Evaluation Outcome Results Reported

A modal response to the question, "Describe the outcomes of these activities, i.e., What data do you have concerning primary referrals reached? families referred?" was "Not addressed to date."

Following are examples of data reported in response to this question:

Virginia. A statewide survey of 342 pediatricians in Virginia conducted on behalf of the Part H agency asked three research questions: 1) To what extent are pediatricians involved in child find efforts; 2) What factors influence pediatricians to make referrals to early intervention programs; and 3) What are pediatricians' perceptions of their educational needs in regard to early intervention. The return rate was 40.18%. Since 88% of the respondents were board certified, the study was skewed in the direction of a well credentialed and sophisticated sample.

The response to the first question showed a high degree of participation in child find among the pediatricians surveyed. The study showed that 72% of the respondents reported that they consulted regularly with early intervention programs; 76% made referrals to appropriate professionals; and 74% made referrals to early intervention programs.

In response to the second question, pediatricians reported that they were more likely to make referrals when they believe early intervention will be beneficial to the child. For example, 95% referred children with vision or hearing disabilities; in contrast, only 55.5% referred when there was known maternal exposure to medication known potentially to cause problems, such as anticonvulsants. Referrals were not made when programs were inaccessible to families. Investigators speculated that if pediatricians had a formal affiliation with early intervention personnel, this might foster referrals. The researchers were surprised by the low numbers of affiliations with pediatric practices, given the fairly high referral rate. Fewer than half of the respondents had early intervention personnel affiliated in some way with their practice. Of those that did, specialties of the affiliated personnel were as follows: nurse practitioner (30.5%), nutritionist (27.1%), social worker (26.5%), educator (17.1%), speech and language pathologist (16.6%), and occupational therapist (15.2%). From these data, it was concluded that among a highly sophisticated sample of pediatricians (those most likely to refer to early intervention), having an in-office affiliation was fairly uncommon, and was not necessarily a factor in generating referrals.

Regarding question three, which pertains to training needs, 94% of the pediatricians indicated that more training in developmental/behavioral pediatrics was needed. The top three requests for continuing education were developmental screening, public and private resources

in early intervention, and orientation to psychological/educational testing instruments.

Southeast Kansas Birth to Three Project (Kansas UAP). In a project serving 100 infants, 28 referrals came from primary physicians and health agencies. Another 15, from parents, were made at the suggestion of physicians and health agencies. The remaining referrals came from community agencies (including social service agencies, preschools, churches, etc.) and from the child find program of the local public school system.

North Carolina-Part H. North Carolina's statewide client information system found referral sources came mainly from the medical community. Specific data were as follows:

Principal Referral Sources	Percent
Public Health Agencies	21.2
Hospitals	19.0
Private Pediatricians	13.8
Developmental Evaluation Centers	12.2
Families	10.0
Social Service Agencies	4.9
Other Early Intervention Programs	4.4
Other Physicians	3.6
Other	10.9

Reviewers of an earlier draft of this synthesis report from the Association of Maternal and Child Health Programs, noting that some Developmental Evaluation Centers receive funds from Title V, which also supports public health agencies, commented that these data illustrate the central role of the public health sector in early intervention referrals.

Texas-Part H. ECI has completed a random sample survey of 10% of families attending ECI programs. Results from this survey, known as the Child-Family Questionnaire, included referral information which indicates that 59% of the children sampled were referred before 9 months of age and 25% were referred before of 4 months of age. There are a few documented cases of the referral of families of children with Down syndrome before birth. Additionally, 56% of the sample had received care in a NICU or special care nursery; 44% had received no special care before initial hospital discharge after birth.

The total number of referrals in FY '91 was approximately 13,000, and the total number of children served was approximately 12,500. This is projected to be approximately 50% of the number of children in need of services in Texas.

Conclusion and Further Questions

This report has sought to consolidate information from diverse programs and agencies. It is hoped that the ideas presented will be of use in assessing and improving communication with primary referral sources. NEC*TAS will continue to solicit information on this subject,

and provide updates as appropriate, and we hope that this Synthesis Report serves as the catalyst for further sharing and learning.

We pose the following questions for readers of this report:

1. What direct methods are states or projects using to determine whether information about early intervention has been given to families by primary referral sources?

2. What additional efficacy/outcome data is available regarding informing primary referral sources and determining the extent to which this generates referrals?

3. What models, programs, or resource materials have been particularly useful for attracting, through primary referral sources, families who have been traditionally underserved and historically underrepresented in early intervention programs (e.g., culturally and linguistically diverse populations, parents with disabilities, minority, low-income, inner-city, and rural populations)?

4. Can anyone provide information on lists or compilations of public awareness and child find materials that have been published in languages other than English?

5. What additional questions would you like NEC*TAS to address on the subject of communicating with primary referral sources?

We welcome anecdotal responses to these questions and other concerns related to the topic of communicating with primary referral sources. Please send responses and comments to NEC*TAS, to the attention of Carol Berman at **ZERO TO THREE**/National Center for Clinical Infant Programs.

Attachment A:
Survey Questions

1. Describe how your project, model, or agency has facilitated the flow of information to primary referral sources, specifically medical personnel (e.g. obstetricians, pediatricians, nurses) and to health facilities to expedite the child find process and provide information on early intervention to families.

2. If different from A, describe how your project, model or agency has facilitated the flow of information to primary referral sources, specifically non-medical personnel and facilities (e.g. child care workers, social service professionals, local education agencies, family support programs and families) to expedite the child find process and provide information on early intervention to families.

3. Describe, if appropriate, effective ways in which primary referral sources have provided information to families and ways in which these initiatives have been facilitated by your project, model, or agency.

4. Describe how your project, model, or agency has facilitated feedback from primary referral sources to determine whether information has been given to families.

5. Identify any procedures for communicating with primary referral sources that have been tried and found to be unsuccessful. If appropriate describe the nature of specific difficulties.

6. If applicable, describe how the difficulties in communicating with primary referral sources have been overcome.

7. Describe, if appropriate, how your project, model, or agency has planned for or implemented training of primary referral sources about basic components of early intervention services available in the state. Identify procedures that have been most useful or promising.

8. Describe the evaluation/efficacy component and tools (if applicable for assessing communication with primary referral sources.

   8a. How do you know whether information is reaching primary referral sources?

   8b. How do you know whether information is reaching families? (e.g., Do early intervention programs ask about referral source at intake? Are these data systematically compiled statewide? In pilot sites?)

9. Describe the outcomes of these activities, i.e., What data do you have concerning primary referral sources reached? What data do you have concerning families referred?

10. Describe the evaluation/efficacy component, if applicable, with respect to planning or implementing training of primary referral sources about the basic components of early intervention services.

11. List any products relative to primary referral sources (such as research reports, manuals, brochures, or training materials) which have been an outgrowth of this project and indicate how one might access them.

Attachment B:
Respondents and Reviewers

Each respondent is identified according to the role played in this document: survey respondent (S), interviewee (I), or reviewer (R). Some respondents played more than one role. The asterisk (*) following each name and address denotes strategies and products identified by respondents, or indicates one or more areas of expertise for which the individual was asked to review the draft.

Arizona

Raun Melmed, M.D. (S)
Educating Physicians in Early Identification of Developmental Problems in the 0 to 3 Population
Developmental Pediatric Associates
5040 East Shea Boulevard, Suite 166
Scottsdale, AZ 85254
#602/443-0050
#602/443-4018 (fax)

* Presentations by team of parent, physician, and state representative to physicians and health-related personnel at various sites; outline of their training module is available on request; developing a protocol for evaluation of behavior in first year of life; devised checklist for primary care physicians for screening purposes and as part of a continuing medical education program.

Inquiries should be directed to:

Melanye Wrighton
Arizona Academy of Pediatrics
1775 East Ocotillo Rd.
Phoenix, AZ 85016
#602/230-1949
#602/230-1771 (fax-telephone before sending fax)

Colorado

Dianne Garner, Part H Coordinator (S)(R)
Pat Tesauro-Jackson (contact person)
Special Education Division
State Department of Education
201 East Colfax, Room 301
Denver, CO 80203
#303/866-6709
#303/830-0793 (fax)

* First Impressions Program; developed self-evaluation tool.

Cindy Unger (S)(R)
Co-Track Information Management System
Children's Health Services
Colorado Department of Health
FCHS/Medical Affairs
4210 E. 11th Avenue
Denver, CO 80220
#303/331-8274
#303/320-1529 (fax)

* Statewide Disability Information & Referral Service Resource Directory.

District of Columbia

Holly Allen Grason, M.A. (R)
Association of Maternal and Child Health Programs
2001 L Street, NW, Suite 308
Washington, DC 20036
#202/775-0436

* Conducting survey on Title V programs and early intervention; has reported studies of maternal and child health and children with special health care needs programs.

Leticia Patiño (R)
Mental Health Law Project
1101 15th Street, NW, Suite 1212
Washington, DC 20005
#202/467-5730
#202/223-0409 (fax)

* Project to enhance awareness of and approaches to underserved populations, including diverse cultures.

Hawaii

Calvin Sia, M.D. (R)
Margo Peter
Medical Home Project of the
Hawaii Medical Association
Hawaii Medical Association
1360 South Beretania
Honolulu, HI 96814
#808/536-7702

* Training of health care practitioners and early intervention personnel with the goal of enabling all children to have a "medical home".

Illinois

Audrey Witzman, Part H Coordinator (S)(R)
Early Childhood Program Unit, S-100
Illinois State Board of Education
100 North First Street
Springfield, IL 62777-0001
#217/524-0203
#217/785-7849 (fax)

* Meetings with perinatal centers and pediatricians; use of ITAP module on medical/health issues taught by a physician; dissemination meetings; brochures (child find (2) and clearinghouse information); newsletter; "Voices for Illinois" materials to parents.

Mary C. Lawlor, ScD. FAOTA, OTR/L (S)(R)
UIC Therapeutic Partnership Project
Department of Occupational Therapy
University of Illinois at Chicago
1919 West Taylor Street, Room 311
Chicago, IL 60612
#312/996-6901
#312/413-0256 (fax)

* Brochure for parents.

Margaret Summerfelt, Project Director (I)(R)
"Watch Me Grow" Demonstration Project (SPRANS Project)
National Easter Seal Society
70 East Lake Street
Chicago, IL 60601
#312/726-6200

* Computerized tracking of at-risk infants.

Iowa

Alfred Healy, Professor and Director (R)
Division of Developmental Disabilities
Department of Pediatrics
University Hospital School
University of Iowa
Iowa City, IA 52242
#319/353-6390

* Has been principal investigator of numerous projects for American Academy of Pediatrics and American Association of University Affiliated Programs.

Kansas

Sharon Rosenkoetter, Ph.D. (S)(R)
Bridging Early Services Transition Project (BEST)
ACCK - 105 E. Kansas
McPherson, KS 67460
#316/241-7754
#316/241-5153 (fax)

* Inservice training; system to exchange information; brochure.

Lorraine I. Michel (S)(R)
Part H Infant-Toddler Program
Kansas Dept. of Health and Environment
Landon State Office Bldg.
900 SW Jackson, 10th floor
Topeka, KS 66612-1290
#913/296-6135
#913/296-6231 (fax)

* Brochures on early intervention services and general information; newsletter; procedural manual.

Juliann Woods Cripe (S)(R)
Southeast Kansas Birth to Three Project
UAP at Parsons
Bureau of Child Research
University of Kansas
2601 Gabriel
Parsons, KS 67357
#316/421-6550 x1767
or 1-800-362-0390 x1859
#316/421-6550 x1864 (fax)

* Brochures, magnets, and telephone index cards in newborn baby kits; physician and agency resource packets.

Maine

Jaci Holmes, Part H Coordinator (Acting) (S)(R)
State Office of Child Development Services
State House Station #146
87 Winthrop Street
Augusta, ME 04333
#207/289-3272
#207/289-5900 (fax)

* Created Health Advisory Group; health and informational brochures; public service announcements.

Maryland

Haidee Bernstein (I)(R)
11105 Stillwater Avenue
Kensington, MD 20895
#301/949-1238 or #202/732-1095 (Tuesday & Thursday)

* Case study of statewide public awareness programs; part-time education specialist at Office of Special Education Programs (OSEP).

Deborah Von Rembow, Resource Development Specialist (S)(R)
Jerry Eileen Perry, Public Awareness Coordinator
Maryland Infants and Toddlers Proram (Part H)
One Market Center, Suite 304
300 W. Lexington Street, Box 15
Baltimore, MD 21201
#410/333-8100
#410/333-3199 (fax)

* Targeted mailings; brochures; referral guidelines disseminated statewide; offer technical assistance conferences and on-site poster sessions.

Renee Wachtel, M.D. (I)(R)
Clinical Director, Comprehensive Evaluation Unit
University of Maryland Department of Pediatrics
Division of Behavioral and Developmental Pediatrics
University Hospital
530 West Fayette Street 5-686
Baltimore, MD 21201
#410/328-8667

* Conducts preservice and inservice training for medical students and residents; has curriculum.

Massachusetts

T. Berry Brazelton, M.D. (R)
Child Development Unit
Children's Hospital Medical Center
300 Longwood Avenue
Gardner House, 5th floor
Boston, MA 02115
#617/735-6948

* Member of the Board of Directors of **ZERO TO THREE**/NCCIP.

Minnesota

Donna J. Peterson, MHS, ScD (R)
Chief, Services for Children with Handicaps
Minnesota Department of Health
Maternal and Child Health Division
717 Delaware Street Southeast
P.O. Box 9441
Minneapolis, MN 55440-9441
#612/623-5000

* Title V agency.

Jan Rubenstein (S)(R)
Diane Bick
Interagency Planning Project for Young Children with Disabilities, Part H
Department of Education
826 Capital Square Building
550 Cedar Street
St. Paul, MN 55101
#612/296-7032 (J. Rubenstein)
#612/297-5979 (D. Bick)
#612/297-7368 (fax--Rubenstein)
#612/296-6244 (fax--Bick)

* Newsletter; established position in Health Department to assist in development of child find procedures; public awareness campaign includes posters, brochures, central directory, flyer; videotape; "Got a question, get an answer" wheel, a guide to the child's first five years.

Mississippi

Stella Fair (S)(R)
Janie Cirlot-New
Project Coach
Mississippi University Affiliated Program
University of Southern Mississippi
Southern Station, Box 5163
Hattiesburg, MS 39406-5163
#601/266-5163
#601/266-5755 (fax)

* Public awareness workshop/seminars, with script and manual available; survey of child care centers on their approaches to public awareness and their satisfaction level; video.

New Mexico

Ginny Munsick Bruno, Project Director (S)(R)
Terry Davis, Staff Assistant
Productive Waiting Project
University of New Mexico Medical Center
Department of Pediatrics
Neonatal/Perinatal Programs
Developmental Care Program
ACC 3 - West
Albuquerque, NM 87131
#505/272-6805
#505/272-6845 (fax)

* Developing training module for primary health care providers; believes building personal relationships and trust is crucial; inservice for developmentalists and personal contact to supplement letters and brochures are helpful.

New York

Frank Zollo, Director (S)(R)
Early Intervention Program
Bureau of Child and Adolescent Health
State Department of Health
Room 208, Corning Tower Building
Albany, NY 12237-0618
#518/473-7016
#518/473-8673 (fax)

* Outline of presentation on training for medical personnel and one specifically tailored for day-care/nonmedical available.

North Carolina

Mary Lynne Calhoun, Ph.D. (S)(R)
Charlotte Circle Outreach
Department of Teaching Specialties
University of North Carolina at Charlotte
Charlotte, NC 28223
#704/547-2531

* Brochures; 2-way staff visits; papers available on parental concerns and building referral networks.

Duncan E. Munn, Part H Coordinator (S)(R)
Developmental Disabilities Section
Division of Mental Health/Developmental Disabilities/Substance Abuse
Department of Human Resources
325 North Salisbury Street
Raleigh, NC 27611
#919/733-3654
#919/733-9455 (fax)

* Brochures regarding Part H (interagency and child find) and referral procedures; presentations at professional meetings; newsletters; surveys; various public awareness campaign materials; direct mailings to pediatricians regarding central directory.

Patricia Fullagar, Investigator (I)(R)
Carolina Policy Studies Program
Frank Porter Graham Child Development Center
CB #8040, 300 NCNB Plaza
The University of North Carolina at Chapel Hill
Chapel Hill, NC 27599-8040
#919/962-7374 or 942-4768
#919/962-7328 (fax)

* Conducted study and developed report on pediatricians and other healthcare professionals' activities and training related to early intervention.

Anne Marie Trepanier, Project Coordinator (S)(R)
MEDical-EDucation Early Intervention Project (MED-ED)
Family, Infant and Preschool Program
Western Carolina Center
300 Enola Road
Morganton, NC 28655
#704/433-2864
#704/438-6457 (fax)

* Site visits; joint home visits; medical personnel assist the project in arranging times and places for project personnel to meet with families; presentations; participants on statewide nursing neonatal discharge planning committee; case study; brochures.

Stuart Teplin, M.D. (R)
Associate Professor
Clinical Center for Study of Development and Learning
CB #7255, 150 Biological Sciences Research Center
The University of North Carolina at Chapel Hill
Chapel Hill, NC 27599-7255
#919/966-4810 or -5171

* Training program; curriculum for medical students and residents.

North Dakota

Greg Gallagher, Project Coordinator (S)
North Dakota Early Childhood Tracking System (NDECTS)
Department of Public Instruction
600 E. Boulevard Avenue
Bismarck, ND 58505-0440
#701/224-2277
#701/224-2461 (fax)

* Brochures; system description; sample protocol; preservice training.

Ohio

Kim Carlson, Project Coordinator (S)
Integrated Preschool Project
Akron Public Schools
65 Steiner Avenue
Akron, OH 44301
#216/434-1661 x3041
#216/434-9515 (fax)

* Yearly reports; communication guidelines; procedure handbook (being developed); activity catalog (being developed) for assisting parents in developing an Individualized Education Program; yearly awareness campaign; brochures; presentations; newsletters; developing integrated curriculum; on-site visitation; joint home visits; parent meetings set up through 0-2 agencies.

Oklahoma

Patrice Dunkelgod, Coordinator (R)
Interagency Coordinating Council
Oklahoma Commission on Children and Youth
4545 North Lincoln, Suite A
Oklahoma City, OK 73105
#405/521-4016
#405/524-0417 (fax)

* Public awareness packets which include pencils, puzzles, magnet, and other creative material; "Sooner Start" program.

South Dakota

Rita Vetch, Part H Coordinator (S)(R)
Department of Education and Cultural Affairs
700 Governors Drive
Pierre, SD 57501-2293
#605/773-4329 or -4478
#605/773-6139 (fax)

* Training for service providers.

Tennessee

Donna DeStefano (S)(R)
Department of Special Education
Peabody College, Box 328
Vanderbilt University
Nashville, TN 37203
#800/288-7733
#615/322-8277
#615/322-8236 (fax)

* Newsletter; "Families as Consumers" packet with lists of resources/services; presentations.

Texas

Julia Kirby (R)
Texas Early Childhood Intervention Program
Department of Health
1100 W. 49th Street
Austin, TX 78756
#512/458-7673
#512/458-7454 (fax)

* Displays; presentations; brochures; mailings; articles in medical journals and newsletters; conferences and training meetings; on-site visits.

Virginia

Corinne Garland (S)(R)
Williamsburg Area Child Development Resources (CDR)
P.O. Box 299
Lightfoot, VA 23090-0299
#804/565-0303
#804/564-0144 (fax)

* Letters, including "thank you" notes to referral sources; brochures; presentations; annual community screening event; inservice training; telephone survey.

Washington

Janet Lenart, ANRP, MN, MPH (S)(R)
Barbara Woodward, OTR, MPH
Susan Janko, Ph.D.
Washington State Department of Health
Parent-Child Health Services
Mail Stop LC-12D
Olympia, WA 98504
#206/753-6060 (Lenart)
#206/586-7868 (fax)

* Regional training; screening clinic; technical assistance; training materials being developed.

Sandy Loerch, Part H Coordinator (S)(R)
Birth to Six Planning Project
Department of Social & Health Services
12th & Franklin Streets
MS: 45201/OB 44P
Olympia, WA 98504-0095
#206/586-5596 or -8696
#206/586-5874 (fax)

* Uses Interim Family Resources Coordinators (IFRCs); public awareness survey.

Wisconsin

Karen Wollenburg (S)(R)
Portage Multi-State Outreach Project
CESA 5
626 E. Slifer Street
Portage, WI 53901
#608/742-8811
#608/742-2384 (fax)

* Progress reports; "thank you" notes to referring practitioner; encourage consumers to send referring physicians letters about their satisfaction with services; brochures; posters; child find resource book.

Wyoming

Kathy Emmons (S)(R)
Wyoming Department of Health
Division of Developmental Disabilities
2020 Capitol Avenue
Cheyenne, WY 82002
#307/777-5246
#307/777-6047 (fax)

* Annual infant conference, includes health care professionals; provide funding for public health nurses to be trained; day-care providers conduct screenings.

Attachment C:
Selected Additional Resources

The process used to develop this synthesis report did not include a literature review. However, in addition to the materials mentioned by respondents, a few publications and materials that shed light on communication with primary referral sources came to our attention in the course of our survey. These are cited below.

Anderson, M. & Goldberg, P. (1991). **Cultural competence in screening and assessment: Implications for services to young children with special needs, ages birth through five.** Minneapolis, MN: NEC*TAS & PACER.

A report of the Cultural Diversity Topic Team of the National Early Childhood Technical Assistance System (NEC*TAS). Contact:

PACER Center, Inc.
4826 Chicago Avenue, South
Minneapolis, MN 55417
#612/827-2966

Annual report: Successful integration of infants and toddlers with handicaps through multidisciplinary training. (1991) Hampton, NH: Ann G. Haggart Associates, Inc.

Includes specific section on "Establishing Supportive Resource Systems." Contact:

Ann G. Haggart Associates, Inc.
219 Drakeside Road, Box 55
Hampton, NH 03842
#603/926-1006

Caring for mothers and children: A report of a survey of FY 1987 state MCH program activities. (1989). Washington, DC: Association of Maternal and Child Health Programs.

Contains highlights of state Title V programs and their work in supporting and coordinating direct health services for women and children, including children with special needs. Contact:

Association of Maternal and Child Health Programs
2001 L Street, NW, Suite 308
Washington, DC 20036
#202/775-0436

Darling, R. (in press). **Referral module: Pennsylvania family-focused early intervention system.**

This document is a detailed module regarding the barriers to referral. For further information, contact:

George A. Ziolkowski, Ph.D.
Director of Statewide Support Initiative for Early Intervention
R.R. 1, Box 70-A
McVeytown, PA 17051-9717
#814/542-2501

Directory of University Affiliated Programs. (1991). Silver Spring, MD: AAUAP.

This is an annual directory of UAP programs and initiatives in early intervention. Contact:

American Association of University Affiliated Programs (AAUAP)
8630 Fenton Street, Suite 410
Silver Spring, MD 20910
#301/588-8252

Early intervention: The physician's role in referral [video]. 1990.

A professionally produced 40-minute videotape with 22-page manual. $32 for tape and manual. Contact:

Beginnings Early Intervention Services of Cambria County, Inc.
406 Main Street, Suite 201
Johnstown, PA 15901-1815
#814/539-1919

Fenichel, E. (1991). **Promoting health through Part H.** Washington, DC: NEC*TAS & NCCIP.

A report of the Health Focus Group of the National Early Childhood Technical Assistance System (NEC*TAS). Contact:

Zero to Three/NCCIP
P.O. Box 96529
Washington, DC 20090-6529
#1-800-544-0155

Proceedings from a national conference entitled "Creating Family-Professional Partnerships: Educating Physicians and Other Health Professionals to Care for Children with Chronic and Disabling Conditions. (in press).

This national conference in Pittsburgh, PA, was sponsored by Beginnings Early Intervention Services of Cambria County, Inc., Pennsylvania Chapter of AAP, and Project Caring. Contact:

Rosalyn Darling
Beginnings Early Intervention Services of Cambria County, Inc.
406 Main Street, Suite 201
Johnstown, PA 15901-1815
#814/539-1919

Proceedings from a national conference entitled "Supporting Children & Families Through Integrated Services" included information on Part H of IDEA. 1991. Unpublished manuscript.

This Baltimore, MD, conference was co-sponsored by American Academy of Pediatricians and the Bureau of Maternal and Child Health Resources Development in the U.S. Department of Health and Human Services. Document available by written request only from:

American Academy of Pediatrics (AAP)
Division of Child and Adolescent Health
141 Northwest Point Boulevard
P.O. Box 927
Elk Grove Village, IL 60009-0927

Proceedings from a national conference on Public Law 99-457: Physician participation in the implementation of the law. 1989. Unpublished manuscript.

This Washington, DC, conference was co-sponsored by American Academy of Pediatrics and the Office of Maternal and Child Health, Bureau of Maternal and Child Health and Resources Development (currently MCH Bureau) in the U.S. Department of Health and Human Services. Document available by written request only from:

American Academy of Pediatrics (AAP)
Division of Child and Adolescent Health
141 Northwest Point Boulevard
P.O. Box 927
Elk Grove Village, IL 60009-0927

Title V in review: Two decades of analysis of selected aspects of the Title V Program. (1989). Washington, DC: Association of Maternal and Child Health Programs.

Currently, AMCHP is conducting a survey of Title V program participation in early intervention activities, as an update to this publication. Expected release date is summer or early Fall, 1992. Contact:

Association of Maternal and Child Health Programs
2001 L Street, NW, Suite 308
Washington, DC 20036
#202/775-0436

Attachment D:
"Selected References" from *Promoting Health Through Part H*

Reprinted with permission from Promoting Health Through Part H (pp. 44-46) by E. Fenichel, 1991, Arlington, VA: NEC*TAS & NCCIP. Copyright 1991, NEC*TAS & NCCIP.

Appendix A

Selected NEC*TAS Publications

Note: These publications have previously been distributed to Part H Infant and Toddler Program Coordinators, Part B, Section 619 Preschool Special Education Coordinators, and Interagency Coordinating Council Chairpersons in all states. For additional information on other relevant products, contact the NEC•TAS Coordinating Office at (919) 962-2001.

Burnim, I., et al. (1990). *Strengthening the role of families in states' early intervention systems.* MHLP/NEC•TAS/DEC.

Available from:
Division of Early Childhood
Council for Exceptional children
1920 Association Drive
Reston, VA 22091-1589
(703) 620-3660

Edmunds, P. et al. (1990). *Demographics and cultural diversity in the 1990s: Implications for services to young children with special needs.* NEC•TAS/PACER.

Available from:
PACER, Center Inc.
4826 Chicago Avenue, South
Minneapolis, MN 55417
(612) 827-2966

Information packet on the financing of early intervention and preschool services. (1990). NEC•TAS.

For availability information, please contact:
NEC•TAS Coordinating Office—Publications Section
CB# 8040, 500 NCNB Plaza
University of North Carolina at Chapel Hill
Chapel Hill, NC 27599-8040
(919) 962-2001

Johnson, B., et al. (1991). *Guidelines and recommended practices for the individualized family service plan* (2nd ed.). NEC•TAS/ACCH.

Available from:
Association for the Care of Children's Health (ACCH)
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
(301) 654-6549

Lindgren, J. (1989). *Bibliography of selected resources on cultural diversity.* NEC•TAS/PACER.

Available from:
PACER Center, Inc.
4826 Chicago Avenue, South
Minneapolis, MN 55417
(612) 827-2966

Meisels, S., & Provence, S. (1989). *Screening and assessment: Guidelines for identifying young disabled and developmentally vulnerable children and their families.* NEC•TAS/NCCIP.

Available from:
National Center for Clinical Infant Programs (NCCIP)
2000 14th Street, North, Suite 380
Arlington, VA 22201-2500
(703) 528-4300

Williams, S., & Kates, D. (1990). *NEC•TAS financing workbook: Interagency process for planning and implementing a financing system for early intervention and preschool services.* NEC•TAS.

For availability information, please contact:
NEC•TAS Coordinating Office—Publications Section
CB# 8040, 500 NCNB Plaza
University of North Carolina at Chapel Hill
Chapel Hill, NC 27599-8040
(919) 962-2001

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Blackman, J.A. (1991). Public Law 99-457: Advance or albatross? *Contemporary Pediatrics, 8*(2), 81-95.

Brewer, E.J., et al. (1989). Family-centered, community-based, coordinated care for children with special health care needs. *Pediatrics, 83*(6), 1055-1060.

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Downey, W.S. (1990). Public Law 99-457 and the clinical pediatrician. Part 1: A description of the federal act and its predecessor. *Clinical Pediatrics, 29*(3), 158-161.

Downey, W.S. (1990). Public Law 99-457 and the clinical pediatrician. Part 2: Implications for the pediatrician. *Clinical Pediatrics, 29*(4), 223-227.

Dunn, W. (1989). Occupational therapy in early intervention: New perspectives create greater possibilities. *American Journal of Occupational Therapy, 43*(11), 717-721.

Farel, A. M. (1988). Public health in early intervention: Historic foundations for contemporary training. *Infants and Young Children, 1*(1), 63-70.

Glascoe, F.P., et al. (1989). The importance of parents' concerns about their child's development. *American Journal of Diseases of Children,* 143, 955-958.

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Gorga, D. (1989). Occupational therapy treatment practices with infants in early intervention. *American Journal of Occupational Therapy, 43*(11), 731-736.

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Guralnick, M., et al. (1988). Pediatricians' perceptions of the effectiveness of early intervention for at-risk and handicapped children. *Developmental and Behavioral Pediatrics, 9*(1), 12-18.

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National Information Center for Children and Youth with Handicaps. (1990, May). *A parent's guide: Doctors, disabilities, and the family.* [Available from NICHCY, P.O. Box 1492, Washington, DC 20013, 1-800-999-5599.]

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